Indiana Interagency Coordinating Council

Minutes, May 12, 2010 EasterSeals Crossroads

Indianapolis, IN

The meeting began @ 10:00AM with workgroup meetings. ICC members in attendance Melanie Brizzi, Donna Driscoll, Dawn Downer, Christina Endres, Melissa Hahn, Becky Haymond, Paul Hyslop, Molly Kitchell, Lora Miller, Jamie Stormont-Smith, and Jim Vento . Absent were Claudia Cummings, Phyllis Kikendall, Susie Lightle, Kimberly Minniear, Kevin Porter, and Sarah Sparks. Members of the public were invited to participate in the council workgroups. Workgroups met until 11AM and Jim Vento, acting chair offered a 10 minute break until the regular meeting began @ 11:10AM with workgroup reports.

WORKGROUPS:

Nature of ICC: This group did not have enough members to meet. No report.

Promoting parent rights: This group discussed some of the challenges parents face, as they comprehend their parent rights. This group identified the need for family's need for information that is sometimes difficult to understand. Families often need to balance their rights with what they feel is the best decision for their child and may feel discouraged in voicing their concerns. Children are in the system for such a short time and families have such a short time to gather and comprehend all the information necessary. It was also noted that families do not often have opportunities to network with other families that often leads to clarification and support of their family rights. The Early Childhood Center at the Indiana Institute on Disability and Community has proposed, as part of their UTS Grant to put together an online family training opportunity to support families through the process of First Steps with sessions offered to reinforce what they first hear from their service coordinator. These sessions would be available 24/7 and accessible via the Internet or CD for family members or interested individuals. The topics would include a pathway through the FS system, with information about each of the key activities that make up the family's and child's experiences within the system. Sections would also identify parent rights at each juncture, service coordination expectations and parent responsibilities.

Dawn asked about the status of the Family Handbook, which has gone through several drafts. Betsy will look for those changes in materials received from the previous ICC facilitator.

Service availability and best practice: Jamie Stormont-Smith (PT) was asked to review the 50 highest "cost" in order to look for 'trends' and consider with her

workgroup where additional cost saving might occur. It was noted that all children had a diagnosis, which she noted is key in as the system is able to bill Medicaid only when a diagnosis is indicated. However, the diagnosis code was not always used. Additionally, children are able to access increased First Steps developmental services with prescriptions from doctors or following medical procedures. This is rehabilitative. With the information present in the files it was sometimes difficult to determine if the focus of the increased services was functional/developmental vs. medical. FS is a developmental model, not a medical model. If a child needs such services then they can be provided but FS guidelines need to be very clear as to why services are needed more than once a week. Insurance is requiring major documentation to pay for services and will pay no more than recommended. It was also noted in the review that rarely did these increased services ever decrease afterwards. There needs to be justification in the beginning and throughout as to why services should be increased or maintained at a higher level. It is also imperative that everyone on the team is aware of purpose for that intervention. **Initial Recommendations:** Changes such as increased services should go through the state (for approval). Required justification for increased services may also remove parent, the ED Team, and medical pressure for increases services. Designate a team leader when children receive a number of services addressing the same outcome so that communication is effective (for example both ST and OT addressing feeding). The ED team cannot make recommendations without accurate documentation.

Statewide Consistency in Service Delivery: It is imperative that the practice manual display consistent information about state policy. The UTS is completing an updated version and will finish within the month, send out to clusters via CD and request feedback. The ICC will be included in this review. After changes are made a second draft will be sent to the state for final approval before distribution.

Transition: The workgroup is exploring how FS can do a better job of transition for families. Michael Conn-Powers came prepared to discuss the possibility of the Early Childhood Center conducting a survey through their UTS contract. The goal would be to do follow-up with families who have left system. There were several ideas about how to gather survey information including sending postcards with info to access online survey, follow-up process needs to be put into place. The decision to do postcards will depend on cost. Melanie Brizzi has info about a survey conducted by child care. The goal of the survey is to identify clusters that are doing a good job and to develop training for others who need additional assistance. The timeline is aggressive.

ICC MEETING:

Following the reports of the workgroups, Jim Vento, acting chair called the Council meeting to order. Corrections to the February minutes were solicited and there were none. Because there was no quorum, acceptance of the Feb minutes will be voted upon at the August meeting.

State Report:

Dawn Downer Part C coordinator reported that the numbers of children were holding steady and that state focus was on maximizing the resources available while being conservative in any new spending of state monies. Efforts have focused fine tuning policies and practices.

First Steps turned in their APR with just a few clarifications requested by the feds, mostly simple wording changes. We are now waiting for a response to those changes which may take several months. FS has also turned in their state plan which is available for viewing on the FS website. The state plan identifies the budget and how we are utilizing state and federal funding for the program as well as assurances of what services and support FS has in place. Indiana utilizes federal funds for infrastructure, SPOE costs, UTS. Indiana provides some funds for direct services but most direct services are paid from other sources, not federal funds.

Efforts continue on the 60-day payment for services policy related to family cost-participation. Other states have similar policy in place. At this time we are awaiting federal approval but do not expect any challenges. Indiana FS is in the process of updating the forms, responding to questions and clarifying expectations with families to get all accounts settled. They are working as well on improved training for service coordinators. Insurance is never billed over the FS rate. It is only billed what the state pays providers. Insurance billing is very difficult and FS is under no obligation to bill insurance for the family's portion of cost participation. Agencies are experiencing higher deductibles required of families for payment of therapy services. Providers need additional training in order to be able to inform families. Indiana's cost participation plan is similar to other states so we do not anticipate any issues from the feds, just waiting for a response. No states have withdrawn from accessing Part C federal funding because of costs.

Lora Miller: Reported on the Federal stimulus funds proposal made by FS. There was 9.7M available and a proposal was submitted to utilize the funds for some new initiatives that were felt would benefit the system and impact the system for some time FSSA amended proposal to request the funds be utilized for direct services. There has been approval and 100% to be applied to direct services. Indiana is looking at severe shortfall, so funds will go to direct services. Service levels are high. \$1M/week. Indiana is looking at 11M shortfall this year. The 9.7M will be applied toward that shortfall. A comment was made that we will continue to have a shortfall every year unless we find a way to spend less. It will depend upon the revenue to determine our final deficit. Molly shared her dissatisfaction with the decision as Indiana had a great opportunity to show some initiative but FSSA, looking at the state's fiscal challenges and determined to utilize the \$ to defray those costs. Molly shared her dissatisfaction with use of federal stimulus funding. Lora noted that we may still need to look into other strategies, including eligibility criteria, in order to continue to pay for services.

***First Steps will continue to have to look at other ways to cut costs to run the system. Are we insuring that the children in the system are meeting the current eligibility criteria and getting the appropriate services to meet. We will have to look at other places to cut costs. Are we insuring that the children are meeting eligibility criteria and getting services to meet their developmental needs? Are children receiving more than they need to meet developmental milestones? Jamie noted that we are not bringing children into the system who are not eligible. One suggestion is to consider 'screening' rather than a full blown evaluation. Jamie noted that a 'screening' is not always enough. There is the need to do more in depth evaluation to identify developmental disability. "We are going to be looking at different ideas to bring economies to the system."

As noted in her workgroup report Jamie Stormont-Smith has been reviewing the 'highest costing' cases in order to help the system consider potential cost-saving measures. The review was not to determine that these children did not need all the services they were receiving but to look at other ways to meet the service-needs of children with significant disabilities. Jamie noted that in several cases providers used the IFSP meeting to review reports and talk with other providers. Oftentimes this is the only opportunity that providers have to 'team' because they are not connected professionally other than with that child. Lora noted that while is important not to limit the quality of services providers need to have reports ahead of time to review. There may be work that can be done prior to the meeting so that the time together is used more efficiently. SC needs to be able to run a quality meeting in order to maximize resources. The IFSP meeting needs to be 'productive' in terms the actual IFSP. Another area in which to minimize provider costs would be for children who are aging out or only receiving services for a short time, or those where the child is clearly eligible. While it is important to have an ED team representative there, many times multiple ED Team members are present that are not needed at that meeting? Jamie noted that we do not always have all the circumstances outlined in the IFSP document and that in no way does FS wish to compromise the needs of the child. Dawn reminded us that FS has a Developmental approach and not a medical approach to providing services to children and families.

Lora announced that Peter Bisbecos. DDRS director's last day is May 21st. He will be moving along to other challenges. Julia Holloway is the new DDRS director. She comes from The Division of Aging and brings with her a background in disability and disability services.

Cluster Reports

Several Cluster reported on activities and challenges that their clusters encounter. There were reports from Clusters A, B, G and I. A summary follows.

Report from Cluster A: Jillian Conden. Cluster A has an oversight council. Their LPCC and SPOE council are combined into one with four cluster committees.

- Child Find-committee looks at where the need is and highlights childfind activities.
 - Have developed a Red-Flag checklist for families (when to be concerned)
 - First Steps Info packets provided to families of children coming out of NICU
 - o Build relationships with community partners
- Provider Relationships and Recruitment
 - o Council supports new providers and Service Coordinators
 - Asks for their needs, issues, helps with provider enrollment, training.
 - ED Team committee.
 - Meets quarterly to resolve issues
- Data Review and Planning
 - Cluster performance planning
 - o Data finds go back to Child Find committee
- Transition
 - These are local committees (county specific) School systems have their own set of issues/concerns and local councils need to be able to address those concerns.
 - FAQ flyer for families includes questions about transition for families. Helps to identify questions they might ask of school.
 - Main transition event for cluster. Transition Fair includes vendors like ASK and Head Start. Panel discussion with families to talk about options, available resources.

Report from Cluster B: Jennifer Higgins. Cluster B is the Northeast LPCC.

- SPOE Oversight
- Provider Recruitment
 - o ED team East and West
 - o Lg # of DT enrolled.
 - Meet and greets to talk with providers
 - o General training needs addressed
 - Webcast meeting so providers can see live or look at later
- Transition East and West
 - Breakfast with LEAs and Service Coordinators. Hold short program talking about common needs.
 - Retreat in the spring includes family perspectives of transition, what a family meeting should look like
- Ouality Assurance Committee
- Child Find E&W.
 - o Amish families (E), Hispanic community groups (W).
 - Visit Physician practices to talk about staff and tell them what FS is about. Talk about paperwork that is needed

 St. Joe Hospital has residency program and they often shadow the SC to see what FS is about.

Report from Cluster G: Stacy Holmes. Did some research about the value of volunteer time. Rate was \$17.57 per hour of volunteer time. Important to value our volunteers. Cluster G has 100 +/- council members divided across committees. These are mostly volunteers. Cluster G had recently held annual meeting and Stacy handed out copies of their annual report. Report identifies the cluster's outcomes and a committee is set up to address each outcome. There is an executive committee in the cluster that is made up of members from each of the counties in the cluster.

- Family Outreach
 - Monitors complaints and concerns
 - Responds to family priorities
 - Hosts Medicaid Waiver Parties for families
 - o Connections group-families gather to hear speaker regarding topic of interest, may discuss current challenges of FS related to families.
 - o Review of survey information from families.
 - o Assemble Family Handbooks distributed at IFSP
 - Maintain cluster resource directory
 - Watch for grants from other community groups
- Provider Issues Committee
 - Host provider forums on core language, challenging behaviors etc.
 - Opportunities for providers to network
 - Annual provider conference
 - o Recruitment and retention issues
 - Outreach activities; attend job fairs at universities to talk to other disciplines, recruitment packets.
 - Maintain an agency list for providers
 - Monitor provider matrix
 - Assist in equipment exchange
- Public Awareness and Child Find
 - Identify and work with physicians in community to be aware of FS services. (Physician packet)
 - Presentations to Residents so that they are more aware of services available and working with families of children with disabilities.
 - o Partner with conferences to provide information
 - Community program presentations (e.g. WIC, Foster Care etc.) to get word out about FS.

Transition

- Hosted "Next Steps" forum, invite families to a developmental preschool to talk to personnel, hold mock case-conference, include ASK & IN*SOURCE to field questions that families may have.
- o Supplies transition information in Family Handbook.

 Special Education School administrators provide training and information to SC so they know with whom they should be in-touch as children leave FS and go into schools.

Report from Cluster I: Jennifer Owens. Cluster I provides services to 15 counties. Work is done regionally and cluster committee works at local level. Some counties meet independently, others who have similar needs and services work together. Same types of committees as other clusters reported. Some differences as they are so spread out geographically. Transition East and West, provides training for co-op districts, invites providers and families to attend. Provider recruitment committee. Data Committee. ED Team meets quarterly to network. Cluster has great attendance at annual IFSP meetings. (96%) and 98% at initial IFSP meeting.

Final Notes:

Dawn Downer expressed her appreciation for the work of the SPOE's and Cluster LPCC and noted her gratitude for clusters as they address issues. Always willing to work towards a solution.

An ICC member asked if an ICC retreat was in the plans for this year. At this time there are no plans for a two day retreat but it was suggested that the ICC take one day to plan for next year building on plans from last year's retreat.

Public Comment

Members of the public were invited to comment on ICC business. Naomi Horton from HEAR INDIANA requested some time to discuss that program. Her report follows.

Of all the conditions for which we screen at birth, hearing loss is the most common. Ninety-five percent of all babies with hearing loss are born to hearing parents. With today's technology 90% of these hearing families are choosing amplification with a focus on listening and spoken English language (rather than American Sign Language).

Hear Indiana would like to thank First Steps for providing hearing aid coverage for our children. In the long run, this provision and a mainstream education in spoken English will save the state of Indiana an estimated \$500,000 per child (K-12).

Hear Indiana wants to ensure that ICC members, Service Coordinators, Providers, and affected families are aware that an interagency agreement exists between FS and the Indiana School for the Deaf. Hear Indiana also requests that the ICC examine if this agreement is appropriate to meet the needs of today's hard of hearing and deaf infants and their families.

In particular under the current agreement, all families identified by the Newborn Hearing Screening program within Cluster G are directed toward a specialized eligibility determination (ED) team from the Indiana School for the Deaf (ISD). Families are told that the team from ISD is the best team (and sometimes the only team) capable of serving their hard of hearing or deaf child. There is no cost to FS for these evaluations.

Currently there are no providers at ISD who meet the nationally recognized requirements for listening and spoken language specialists. There is currently no provider on the ED team from ISD who specializes in the communication modality chosen by 90% of our FS families. Therefore, Hear Indiana kindly asks the ICC to review the decision to direct all babies with hearing loss to this ED team.

Additionally ongoing services for children who listen and speak are not as accessible as services from the Indiana School for the Deaf (which believes in ASL as the first language of instruction). Services from the Indiana School for the Deaf are always free to families as they are appropriated via an \$18 million line item budget. Parents who choose providers who specialize in English spoken language instruction are, however, subject to cost participation.

Finally, FS providers and families should be aware that recent trainings provided by the Indiana School for the Deaf (e.g., Outreach Services or SKI-HI) continue to suggest an advantage to including sign language in early intervention. In line with the vision of the ICC, parent choice must be honored, and if families are not interested in sign language instruction, they should not automatically be referred to the Indiana School for the Deaf or their ED team.

Final Note: Outreach Services for Deaf and Hard of Hearing Children is the outreach and assessment department of and for the Indiana School for the Deaf. While ISD has launched a branding campaign to suggest that Outreach Services for Deaf and Hard of Hearing Children is a separate entity, ISD has one budget and more importantly one board of directors.

Hear Indiana welcomes comments or questions via email to info@hearindiana.org.

Naomi Horton, MS, CCC-SLP

There being no additional business or comments, a motion was made @ 2:45PM to adjourn the ICC meeting. The motion carried.

Betsy Traub, Staff Support Comments/corrections to etraub@indiana.edu or 812-855-6508